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Preface

Welcome to the 2004 Annual Report o
f the New Zealand Paediatric Surveillance Unit (NZPSU). This is the seventh of its kind since the Unit was established in 1997.

The NZPSU was established with funding from the Ministry of Health in order to undertake surveillance of acute flaccid paralysis (AFP) for the Ministry of Health's National Certification Committee for the Eradication of Poliomyelitis (NCCEP). The opportunity was taken for the study of other uncommon high impact conditions, most of which has been undertaken by paediatricians with a particular research interest.

Time spent in this activity (responding monthly, responding with case material, and reading protocols and the annual report) is considered by the Royal Australasian College of Physicians as eligible for Maintenance of Professional Standards (MOPS) points. Please see appendix 1 for a letter from the College outlining the details.

Ongoing Studies

Acute Flaccid Paralysis (AFP)

- There were 12 cases of AFP in New Zealand in 2004, giving an annual incidence rate of 1.5 per 100,000 children < 15 years.
- None of the cases notified was due to polio.

Haemolytic Uraemic Syndrome (HUS)

There were seven children with HUS in 2004, giving an incidence rate of 0.9 per 100,000 children <15 years.

Perinatal HIV Exposure (HIV)

There were 10 notifications in 2004, compared to 12 in 2005.

Congenital Rubella Syndrome(CRS)

There were no cases of CRS reported in 2004.

Inborn Errors of Metabolism (IEM)

There were eight notifications of IEM in 2004.

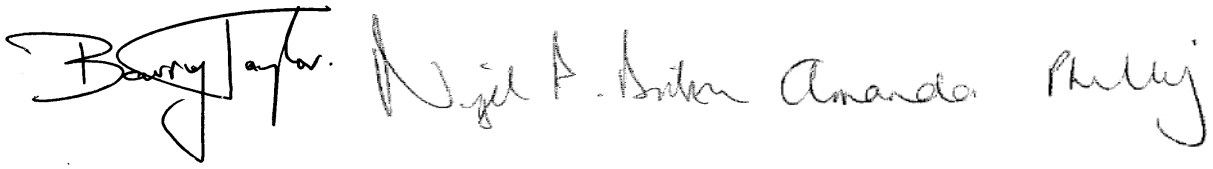
Pertussis
There were 52 cases reported during the first nine months of this study.

Vitamin K Deficiency Bleeding (VKBD)
There were three notifications in 2004, one less than the four notified in 2003.

Prolonged Infantile Cholestasis (PIC)
There have been 50 notifications to the study of prolonged infantile cholestasis, with 32 questionnaires returned to date.

The ongoing success of the NZPSU is largely due to the high level of support from New Zealand paediatricians who have taken the time to provide information on the conditions under surveillance.

We would like to acknowledge the ongoing funding from the Ministry of Health.



Barry Taylor Nigel Dickson Amanda Phillips

Introduction

Surveillance is important to monitor both the incidence of emerging conditions and the effectiveness of prevention measures. The Paediatric Society of New Zealand (PSNZ) had for some years promoted the establishment of a unit that could regularly request specialist paediatricians to report on a number of conditions and this led to the establishment of the New Zealand Paediatric Surveillance Unit (NZPSU) in October 1997.

The aim of the NZPSU is to facilitate and improve the knowledge of uncommon high-impact childhood conditions in New Zealand. These conditions are of sufficiently low incidence or prevalence that case ascertainment on a national scale is needed to generate adequate numbers for meaningful study. The method was developed in the United Kingdom by the British Paediatric Surveillance Unit (BPSU) and has been used there since 1986. Subsequently, it has been introduced into several other countries, including Australia, and is used by some other specialist groups.

The core activities of the NZPSU are funded through a contract with the Ministry of Health to provide active surveillance of acute flaccid paralysis (AFP). The World Health Organisation (WHO), as part of the global eradication process, requires such surveillance to confirm New Zealand is free of poliomyelitis. Since the establishment of the NZPSU, the number of conditions under surveillance has increased and now includes eight high impact childhood conditions.

The NZPSU is a member of the International Organisation of Paediatric Surveillance Units (INoPSU).

Aims

The aims of the NZPSU are:

- To operate a system for monitoring acute flaccid paralysis, as part of the global certification of eradication of poliomyelitis, required by WHO.
- To facilitate national surveillance and improve the knowledge of uncommon high-impact childhood conditions in New Zealand.

How the Surveillance System Works

The method of surveillance is based on that developed in the United Kingdom in 1986 by the British Paediatric Surveillance Unit (BPSU). It has subsequently been used for the monitoring of rare childhood conditions in several other countries, including Australia, and also by other specialist groups.

Paediatricians in New Zealand gave their support to the surveillance system after the concept was discussed at an annual meeting of the Paediatric Society of New Zealand. A database of eligible clinicians, which included all paediatricians and other specialists working predominantly with children, was developed using the specialist register and the membership list of the Paediatric Society. All eligible clinicians were contacted and invited to participate. Those who agreed were provided with study protocols, which included definitions of the conditions under surveillance, specific reporting instructions, and a contact telephone number. Efforts are made to keep up-to-date with the paediatric specialist work force.

Every month participants are sent either a reply-paid card or an email (depending on their preferred method of reporting) to report whether in the previous month they have seen any cases of the conditions under surveillance. However, cases of AFP are also required to be reported immediately by phone to the NZPSU. When a case of any of the conditions is reported, the reporting clinician is sent a short questionnaire to complete on the case. The identity of the case remains anonymous. Duplicate notification is recognised by a code derived from the child's initials and date of birth.

Where possible, cases are regularly compared with other data sources such as hospital discharge data, notifications to the local Medical Officer of Health, and the New Zealand AIDS Epidemiology Group.

It is envisaged that some of the conditions under surveillance will be ongoing, while others will be on for a finite period, usually two or three years.

Regular surveillance reports are made to the Ministry of Health specifically updating the progress with AFP surveillance.

Inclusion of New Conditions

A Scientific Review Panel (SRP) has been established primarily to consider the inclusion of new conditions into the scheme (see *Table 1* for details on members of the SRP). A study is eligible for consideration in the scheme if the condition of interest is:

- a relatively uncommon high-impact childhood condition (or an uncommon complication of a more common disease); and
- of such a low incidence or prevalence as to require ascertainment of cases on a national scale in order to generate sufficient numbers for study; and
- the SRP may also consider inclusion of short-term or geographically limited studies of comparatively more common conditions.

It is important for the success of the scheme that the workload of the mailing list is kept to a minimum. Accordingly, the SRP must be certain that studies conducted through the NZPSU are well designed and worthwhile. The SRP will take into consideration the scientific interest and public health importance of the proposed study, its methodology, and the suitability of the condition for ascertainment through the NZPSU scheme. Studies depending on immediate reporting and/or sample collection, or requiring the participation of other specialties, are less likely to be suitable.

***Table 1*: The Members of the NZPSU Scientific Review Panel (SRP)**

Member	Institution
Professor Barry Taylor	Dunedin School of Medicine
Dr Nigel Dickson	Dunedin School of Medicine
Dr Alison Roberts	Ministry of Health
Professor Elizabeth Elliot	Australian Paediatric Surveillance Unit
Dr Jeff Brown	Palmerston North Hospital
Professor Brian Darlow	Christchurch School of Medicine
Professor Diana Lennon	University of Auckland

Surveillance Activities in 2004

There were nine conditions under surveillance in 2004.

In 2004, 210 clinicians participated in the system. The average response rate to the monthly report card/email was 94%.

We are very pleased with the ongoing high response rate from the whole of the country.

Respondent Workload
Minimising the extra workload that the system imposes on paediatricians is a key factor for its success. The range of conditions under surveillance and their incidence needs to be kept under review.

Table 2 shows the percentage of clinicians on the mailing list that reported cases during 2003 and 2004. The table shows that in 2004, 127 of the participants did not report any cases, with four reporting five or more, compared to zero in 2003.

Overall, more notifications were required for the conditions under surveillance in 2004 than in 2003.

***Table 2*: Respondents Workload 2003 & 2004**

Notifications	2003		2004	
	No.	%	No.	%
None	143	75	127	61
One	26	14	38	18
2-4	22	11	41	19
5 or more	0	0	4	2

In 2004, the NZPSU monitored nine uncommon childhood conditions *(Table 3).* Some of the protocols and questionnaires used were adapted from those used by the Australian Paediatric Surveillance Unit.

Table 3: **Conditions Under Surveillance in 2004**

Condition	Surveillance started	Principal Investigator(s)
Acute flaccid paralysis	October 1997	Dr Nigel Dickson Dr Paul Shillito
Haemolytic uraemic syndrome	January 1998	Dr William Wong
Congenital rubella syndrome	January 1998	Professor Diana Lennon
Perinatal HIV exposure	January 1998	Dr Nigel Dickson Dr Lesley Voss
Vitamin K deficiency bleeding	January 1998	Professor Brian Darlow
Idiopathic nephrotic syndrome	July 2001-July 2004	Dr William Wong
Inborn Errors of Metabolism	January 2004	Dr Nikki Kerruish Dr Callum Wilson
Pertussis	July 2004	Professor Cameron Grant
Foregut and Hindgut Malformations	January 2004	Dr Michael Sullivan

Final Reports for Completed Studies

IDIOPATHIC NEPHROTHIC SYNDROME (INS)

Dr William Wong

Please note this is an interim final report. The final report will be published in the 2005 NZPSU Annual .

Recruitment of new cases of INS ceased 30 June 2004. Twelve month follow up is incomplete for those children who entered the study between March and 30 June 2004. Total of 51 children were reported. There 36 males, 15 females, with mean age of 6.25 years (median 5.0years, 95% CI 4.93-7.24) The ethnic composition was 27 New Zealand Europeans, 5 Pacific Island, 4 Maori, 12 from Asia/Indian subcontinent and other countries.

Presenting Clinical Features

	N (%)
Microscopic haematuria	40 (78.4)
Hypertension	14 (27.4)
Normal renal function	51 (100)

Initial Treatment

	N (%)
Corticosteroids	50/51 (98.0)
Albumin infusion	13/51(25.5)
Antibiotic prophylaxis	38/51(74.5)
Aspirin prophylaxis	9/51(17.6)
Diuretics	15/51(29.4)
Pneumococcal vaccine	18/51(35.0)

Initial data indicate that a large number of children have microscopic haematuria at presentation. All patients except one (refused steroids later found to have focal segmental glomerulosclerosis) were given a trial of steroid therapy. Subsequent management was determined by steroid responsiveness. Twelve month follow-up data on whole cohort will be reported on in the definitive publication.

INFLAMMATORY BOWEL DISEASE (IBD)

Dr A Wesley, Dr S Mouat, Dr J Yap, Dr S Chin

The reporting for this study is now complete. A full and final report will be presented in the 2005 NZPSU Annual Report.

Brief Reports on Selected Conditions

ACUTE FLACCID PARALYSIS (AFP)

Dr Nigel Dickson

Ongoing study started in October 1997

Introduction

To confirm the absence of poliomyelitis WHO requires a surveillance system to be in place:

1. That captures an annual incidence of acute flaccid paralysis (AFP), not due to poliomyelitis, of at least one per 100,000 children < 15 years.

2. In which 80% of cases of AFP have two stool samples taken at least 24 hours apart, within 14 days of onset tested negative for wild polio virus in a WHO-accredited laboratory.

Telephone notification of all cases of AFP is required by the NZPSU to ensure that the necessary stool containers are dispatched in time to the notifying paediatrician.

Key Results for 2004

- There were 12 cases notified to the NZPSU in 2004.
- Information has been obtained on all of these children including follow-up information two months after diagnosis.
- Eleven AFP cases were from the North Island, with the remaining one from the South Island
- Ten males, two females
- Age range 15 months to 14 years, median age four years.
- No seasonal variation.
- The overall incidence was 1.5 per 100,000 children < 15 years.
- A diagnosis of Guillain-Barre Syndrome (GBS) has been made in seven of these cases, *staphylococcal aureus* sepsis in one, Bickerstaff's Brain Stem Encephalitis in another, with the remaining three cases unknown, but not polio.
- All 12 cases have been discounted as Polio by the National Certification Committee for the Eradication of Polio (NCCEP).

- Analysis of stool samples satisfying the WHO criteria was only complete for six of the seven children.

***Table 4*: Percentage of AFP cases with adequate stool samples (or otherwise)**

Category	Stool samples	
	No.	%
2 stool samples within 14 days of onset of paralysis	6	50.0
2 stool samples, but one or both not within 14 days of onset of paralysis	1	8.3
1 stool sample	0	0
No stool samples	5	41.6

Comment
The system successfully captured the required rate of AFP, however the rate of stool testing (50%) is not meeting the WHO criteria (80%). The NZPSU appreciates the support from clinicians in making telephone notifications of AFP and attempts to ensure that timely stool specimens are sent to ESR for appropriate testing.

Even though the WHO believes Polio to have been eradicated from the Western Pacific region, ongoing surveillance of AFP, is likely to be required for some years. This will require the continued telephone notification of all cases of AFP, including those with a definitive diagnosis such as Guillain-Barré syndrome etc. A challenge has always been to utilise a non-specific case definition – such as 'acute flaccid paralysis' – in a health system where a more definitive diagnosed for children with such symptoms is likely to be made.

VITAMIN K DEFICIENCY BLEEDING (VKBD)

Professor Brian Darlow

Ongoing study started in January 1998

There were three cases reported to NZPSU in 2004.

PERINATAL EXPOSURE TO HIV (HIV)

Dr Nigel Dickson, Dr Lesley Voss

Ongoing study started in January 1998

In 2004, there were 10 notifications to the NZPSU of infants/children born to women infected with HIV. Of these, one notification was of a perinatally-infected child born overseas.

Only one report was of a child known to have been infected with HIV. This child had been born in New Zealand in late 2003 to a mother whose HIV had not been diagnosed prior to delivery.

Of the remaining eight babies born in New Zealand, none are believed infected with HIV (although some are still awaiting final confirmation):

- Five were born to mothers whose HIV had been diagnosed before the pregnancy, and three during her pregnancy.
- Four of the mothers were African, two European and two of other ethnicities
- All the mothers were given antiretroviral treatment during pregnancy, four of the eight were delivered by caesarean section, and none of the babies were breastfed.

These figures show the success that can be achieved in the prevention of perinatal transmission of HIV when the infection is diagnosed in a mother prior to delivery, as it would be expected to occur in about a quarter of affected pregnancies without specific measures (antiretroviral therapy, care with means of delivery, and avoidance of breast-feeding) being taken.

While to date there are no children reported to the NZPSU, or known to the AIDS Epidemiology Group, with perinatally acquired HIV, born in New Zealand in 2004, that does not mean that no infection occurred. HIV infection may not be clinically obvious for many years. In fact, in view of the low priority given to HIV diagnosis among pregnant women, it is highly likely that there are a number of as yet undiagnosed children in New Zealand.

CONGENITAL RUBELLA (CRS)

Professor Diana Lennon

Ongoing study started in January 1998

There were no cases reported in 2004.

INBORN ERRORS OF METABOLISM (IEM)
(Urea cycle, amino acid, organic acid disorder or fatty acid oxidation defect).

Dr Nikki Kerruish, Dr Dianne Webster, Dr Callum Wilson, Dr Esko Wiltshire

Study commenced January 2004

There were eight notifications that fulfilled the protocol criteria and questionnaires have been returned for all cases. Brief details are given below.

Disorder	Age at diagnosis	Sex	Region	Reason for diagnosis
Holocarboxylase synthetase deficiency	newborn	M	Auckland	Family history, clinical symptoms:lethargy poor feeding, tachypnoea
Hyperphenylalaninaemia	<1 month	F	Auckland	Newborn screening
Phenylketonuria	<1 month	M	Auckland	Newborn screening
Ornithine transcarbamylase deficiency	prenatal	M	Auckland	Family history, prenatal molecular genetic testing
Ornithine transcarbamylase deficiency	14 years	F	Manawatu	Clinical symptoms (acute confusional episode)
Phenylketonuria	< 1 month	F	Hawkes Bay	Newborn screening
Beta ketothiolase deficiency	6 months	F	Auckland	Clinical symptoms (severe ketosis, out of keeping with underlying mild infection)

Multiple acyl co A dehydrogenase deficiency (glutaric acidaemia type 2)	1 month	F	Auckland	Clinical symptoms (neonatal encephalopathy)

PERTUSSIS: hospitalised infants and young children (<12 months)

Associate Professor Cameron Grant, Professor Keith Grimwood, Dr Maud Meates-Dennis, Dr Ross Nicholson, Dr David Graham, Dr Pam Jackson.

Study commenced July 2004

Aims:

1. To determine the burden of disease from hospitalised pertussis, with special emphasis on the duration of hospitalisation, use of intensive care, death and disability
2. To describe geographical variation in disease severity
3. To describe the methods currently used to diagnose pertussis and the time form onset of symptoms to diagnose.

Active surveillance began in July 2004. All hospitals in New Zealand that provide inpatient paediatric care are participating in this project, with ethical and managerial approval obtained from each centre.

Number of Cases Notified:
As of March 7 2005, 52 cases (excluding duplicates) had been notified, and 48 questionnaires returned. Notifications came from all around New Zealand with the highest numbers from Auckland (18) and Christchurch (11), and smaller numbers from Wellington, Whangarei, Whakatane, Waikato, and one or two notifications from most paediatric centres in New Zealand.

Data Management and Web Page:
The NZPSU and Paediatric Society of New Zealand (PSNZ) have arranged for the questionnaire to be available on the NZPSU page of the on the PSNZ Website, under the “Studies currently on the report card” section. Paediatricians can download the questionnaire from here if they wish ***and allows online completion and return of questionnaires***.

Other Aspects:
Ethical approval has been given for obtaining a list of positive laboratory results of pertussis from each of the 6 centres where there is a co-investigator (Kidz First, Starship, Waikato, Wellington, Christchurch and Dunedin), to check that cases have not been missed.

Contact has also been made with Dr David Phillips, Programme Leader, Population & Environmental Health Programmes, ESR. He will provide ESR

notification data that can be used as the alternative data source to use to capture-recapture methodology to estimate the degree of under reporting.

PROLONGED INFANTILE CHOLESTASIS

Dr Alison Wesley

Study commenced 2002

There have been 50 notifications to the study of Infantile Cholestasis during 2004. To date 32 completed questionnaires have been returned which indicated some of the reported were duplicates.

Of the 26 children on whom a questionnaire has been received, the cause of the conditions were:

	Number
Jaundice associate with prematurity ± parenteral nutrition.	8
Biliary Atresia	9
Idiopathic Cholestasis	6
Neonatal Hepatitis	2
CMV Hepatitis	1

Children with Biliary Atresia

There have been nine children reported with biliary atresia and it is known that there is one other child with this condition who has received a liver transplant whose questionnaire has not yet been returned.

Of these 10 children, five were male and five female. Five were Maori, four were European, and one another ethnicity.

So far three have received liver transplants, three are awaiting transplant and two are currently being assessed. The mean age at first medical assessment of these children was eight and a half weeks and for the Kasai operation 71 days (28-113). All except one who was not seen until 6 months of age received a Kasai operation.

HAEMOLYTIC URAEMIC SYNDROME (HUS)

Dr William Wong

Ongoing study started in January 1998

There were seven children with HUS in 2004. All except one lived in the upper North Island. Three children had E coli 0157 H7 isolated from their stools. Two of the seven had atypical HUS, one following streptococcal sepsis, the other idiopathic, due to an inherited complement factor deficiency. This patient has subsequently developed chronic renal failure. Median time to diagnosis was

seven days. Five of seven required acute peritoneal dialysis and all have a complete initial recovery.

KEY FINDINGS AND RECOMMENDATIONS FROM THE EVALUATION QUESTIONNAIRE FOR PARTICIPANTS OF NZPSU SCHEME

The success of the NZPSU process is dependent on paediatricians reporting the conditions under surveillance in a timely manner and completing relevant information. In 2004 all paediatricians involved in the scheme were sent a questionnaire asking specific questions about their views and experiences. This was based on that developed by the Australian PSU.

Appended (Appendix2) to this report are the results to each question that have been previously posted on the NZPSU page of the PSNZ website.

All the 208 paediatricians enrolled in the scheme were sent a questionnaire and 85% were returned.

Key findings and action that will be taken as a result of the survey

Over two thirds (67%) of the participants said that they read the study protocols and questionnaires "always" or "most of the time", and just over half (54%) found the protocols educationally "always" or "usually" useful.

There were similar findings in the audit of the Australian PSU, in which a third of the respondents said the information on the studies had informed or changed their practice, 62% had found the definitions and protocols educationally useful.

The Australian findings, that we have also found here, resulted in the Royal Australasian College of Physicians making involvement in these PSU activities eligible for MOPS points.

The audit found that NZPSU Annual Report to be a useful publication. "Some" or "all" of it, was read by 63% of the respondents. Of these, over 90% found it "very" or "somewhat" informative. It was the most common source of information of the results of studies, being mentioned as where results by 59% of the respondents. The other major source of this was presentations and posters at Paediatric Society Annual Scientific Meetings. Similarly, the Australian audit found that two thirds had read their most recent Annual Report, most of whom had found it useful.

The NZPSU will encourage the principal investigators to provide an update of the findings from ongoing studies for the Annual Report and also to provide a fuller report on completed studies. We do appreciate that some of these might not be available for the report immediately following the completion of a study as the protocol might require the collection of follow-up information.

Of the respondents, nearly 70% received and returned the monthly 'card' by email. Of those that used the post, thee quarters said they would prefer to use email. Very few (<4%) felt the current format of the emailed 'cards' could be improved.

The NZPSU will in future consider process to be predominantly electronic using email as the preferred means of communication, with provision for the small minority who prefer to use post.

Only two respondents always found completing and returning the NZPSU report cards a burden, although a further 6% said this was sometimes so. About two thirds would be willing to report more cases by fax/phone (as currently for AFP) if an important reason is provided, and over a quarter would not be or were unsure. A similar proportion would not object to the collection samples (including blood) for other conditions as it currently required for AFP surveillance.

Studies requiring telephone reporting will be considered in exceptional circumstances. The collection of specimens as part of the surveillance process, while not being ruled out would only be considered if there were convincing reasons for it.

Only six respondents (3%) were concerned about providing de-identified clinical information, and a further 18 (10%) were unsure.

Ethical approval that will ensure all studies meet ethical and legal guideline will continue to be required for all studies.

About half (47%) of the respondents thought the current the number of conditions on the card to be all right, and a further 40% that "more would be fine", and 8% that there "should be fewer".

The number of conditions on the card when the survey was undertaken was not in general considered a burden, and many thought there could be more. Of course, in increasing the number

consideration would be given to how much extra work this would entail which would be dependant in the incidence of the conditions.

Of those who had ever reported a case, nearly one in five had felt there had been too long a delay between reporting a case and receiving a questionnaire; nearly a third had not found the questionnaire easy to complete, and for a quarter the case specific data always readily available.

While for most people none of these issues were a problem, it is important that investigator ensure that the questionnaire is distributed in a timely manner – and post it on the NZPSU page of the Paediatric Society website. The investigators will also be asked to make it as easy to complete as possible and only ask for information that would normally be collected for the condition reported.

Conditions Ever Monitored by NZPSU

Table 5: **All conditions ever monitored by the NZPSU**

Condition	Abb.	Commenced	Concluded
Acute flaccid paralysis	AFP	October 1997	Ongoing
Haemolytic uraemic syndrome	HUS	January 1998	Ongoing
Congenital rubella syndrome	CRS	January 1998	Ongoing
Perinatal HIV exposure	HIV	January 1998	Ongoing
Vitamin K deficiency bleeding	VKDB	January 1998	Ongoing
Neonatal herpes simplex infection	HSV	January 1998	December 2000
Subdural haemorrhage (<2 years)	SDH	January 1999	December 2002
Retinopathy of prematurity (stage III)	ROP	January 1999	December 2000
Diabetes mellitus	DM	January 1999	December 2000
Fetal alcohol syndrome	FAS	July 1999	December 2001
Kawasaki disease	KD	January 2001	December 2002
Bronchiectasis	BE	January 2001	December 2002
Idiopathic nephrotic syndrome	INS	July 2001	Ongoing
Inflammatory bowel disease	IBD	January 2002	December 2003
Prolonged Infantile Cholestasis	PIC	January 2004	Ongoing
Foregut and Hindgut Malformations	FHM	January 2004	December 2005
Pertussis	Pert	July 2004	Ongoing
Inborn Errors of Metabolism	IEM	January 2004	Ongoing

International Network of Paediatric Surveillance Units (INoPSU)

Establishment of INoPSU
The network was formed in August 1998 at a meeting of 10 Paediatric Surveillance Units expressing a desire to link with each other. This took place at the 22nd International Congress of Paediatrics in Amsterdam, The Netherlands. The first INoPSU conference was held in 2000 in Canada and was attended by representatives of the existing units. Subsequent meetings have been held in York, England in 2002 and Lisbon, Portugal in 2004. Dr Nigel Dickson has attended these recent meetings.

Mission
The mission of INoPSU is the advancement of knowledge of uncommon childhood infections and disorders, and the participation of paediatricians in surveillance on a national and international basis so as to achieve a series of benefits.

Aims
- facilitating communication and cooperation between existing national paediatric surveillance units;
- to assist in the development of new units;
- to facilitate sharing information and collaboration between researchers from different nations and scientific disciplines;
- to share information on current, past and anticipated studies and their protocols, and on conditions that have been nominated for surveillance but are not selected;
- to encourage the use of identical protocols to potentially enable simultaneous or sequential collection of data on rare paediatric disorders in two or more countries;
- to share and distribute information of educational benefit to constituent units, notably on study and surveillance methodologies;
- to share school techniques and models of evaluation for units;
- to peer review and evaluate existing and proposed units;
- to identify rare disorders of mutual interest and public health importance for co-operative surveys through each national unit;
- to collaborate with, and provide information to, other groups interested in rare childhood diseases such as parent support groups;
- to respond promptly to international emergencies relating to rare childhood conditions where national and international studies can make a contribution to science or public health.

Members of INoPSU

Founding members:

- Australian Paediatric Surveillance Unit (APSU)
- British Paediatric Surveillance Unit (BPSU)
- Canadian Paediatric Surveillance Programme (CPSP)
- German Paediatric Surveillance Unit (ESPED)
- Latvian Paediatric Surveillance Unit (LPSU)
- Malaysian Paediatric Surveillance Unit (MPSU)
- Netherlands Paediatric Surveillance Unit (NSCK)
- New Zealand Paediatric Surveillance Programme (NZPSU)
- Papua-New Guinea Paediatric Surveillance Unit (PNGSU)
- Swiss Paediatric Surveillance Unit (SPSU)

Additional Members

Welsh Paediatric Surveillance Unit (2000)
Portuguese Paediatric Surveillance Unit (2001)
Irish Paediatric Surveillance Unit (2001)
Greece and Cyprus Paediatric Surveillance Unit (2004)

Associate Members

Trinidad and Tobago Paediatric Surveillance Unit (2004)
British Ophthalmologic Surveillance Unit

Administration of the Association

In order to carry out the aims and direct the activities of INoPSU a secretariat has been set up. From 2004 Professor Rudi von Kris (ESPED) will act as Convenor, taking over from Professor Elizabeth Elliott (APSU) and Dr R Pereira (NSCK) will act as deputy Convenor. Richard Lynn (BPSU) will act as communications liaison.

International Collaboration

New Zealand paediatricians who are interested in undertaking international studies, or compare the rates of uncommon disease between countries, are encouraged to consider using INoPSU for this purpose. Please contact Nigel Dickson for further information.

Table 6: **Members of INoPSU**

Country	Unit	Email	Website
Australia	APSU	apsu@chw.edu.au	http://apsu.inopsu.com
Britain	BPSU	enquires@rcpch.ac.uk	http://bpsu.inopsu.com
Canada	CPSP	cpsp@cps.ca	www.cps.ca/english/cpsp
Germany	ESPED	heinrich@med.uni-duesseldorf.de	www.esped.uni-duesseldorf.de/
Ireland	IPSU	gilld@iol.ie	
Latvia	LPSU	aspedlat@com.latnet.lv	
Malaysia	MPSU	jho@pc.jaring.my	
Netherlands	NSCK	r.pereira@pg.tno.nl	
New Zealand	NZPSU	nzpsu@stonebow.otago.ac.nz	www.paediatrics.org.nz
Papua New Guinea	PNGPSU	hopepng@datec.com.pg	www.hopeww.org/where/png/png5.htm
Portugal	PPSU	ana.moreira@sb.com	
Switzerland	SPSU	hans-peter.zimmermann@bag.admin.ch	
Wales	WPSU	John.Morgan@eglam-tr.wales.nhs.uk	

INoPSU website: www.inopsu.com

Table 7: **Characteristics of the Paediatric Surveillance Units**

Country	Population ($x10^6$<15years)	Established	Approx. no respondents
Australia	3.9	1992	1000
Britain/Eire	12.8	1986	2200
Canada	7.5	1996	2400
Germany	12.0	1992	500*
Ireland	1.3	1996	150
Latvia	0.4	1996	22
Malaysia	7.6	1994	400
Netherlands	3.0	1992	640
Papua New Guinea	1.9	1996	40
Portugal	1.6	2000	2000
New Zealand	0.83	1997	200
Switzerland	1.3	1995	45*
Wales	0.65	1994	135*

* Heads of Paediatric Centres

Table 8: **Conditions Under Surveillance Worldwide 2004**

Conditions Under Surveillance	Country
Acute encephalitis	Portugal
Acute flaccid paralysis	Australia, Canada, New Zealand
Acute rheumatic fever	Switzerland, Canada
Adverse effects from complementary or	Australia, Wales
Alcohol & Children	Ireland
Anaphylaxis following food ingestion	Australia
Asthma deaths	Malaysia
Autism under 5 years	Ireland
Atypical mycobacterial infections	Netherlands
Ataxia	Netherlands
Atypical tuberculosis infection	Netherlands
Barter like syndromes	Germany
Central nervous system(acquired	Netherlands
CHARGE association/syndrome	Canada, Germany
Childhood conversion disorder	Australia
Chronic intestinal lung disease	Spain
Complicated pneumonia including empyema	Wales
Congenital cytomegalovirus infection	Australia
Congenital myotonic dystrophy	Canada
Congenital malformation after maternal use of	Netherlands
Congenital rubella	Australia, Britain, Canada, New
Congenital toxoplasmosis	Britain
Diabetes mellitus/insulin-dependent/<5 years	Germany, Latvia
Down's Syndrome	Netherlands
Fetal alcohol syndrome	Australia
Fragile X	Ireland
Group B streptococcal infections (neonatal)	Portugal, Germany
Haemolytic Uraemic Syndrome	New Zealand
Haemorrhagic disease of the newborn	Australia, Britain, New Zealand
Hereditary periodic fever syndrome	Germany
Hemoglobinopathy	Netherlands
Hepatitis C virus infection	Canada, Australia
Haematology/oncology	Latvia
Henoch-Scholein purpura	Netherlands
HIV/AIDS +/- perinatal exposure to HIV	Australia, Britain, New Zealand
Hypernatrenia	Netherlands, Wales
Hyperbilirubinaemia	Germany, Britain
Hypocalcemic salt-losing tublopathies	Spain
Inborn errors of metabolism	New Zealand
Idiopathic nephrotic syndrome	New Zealand, Netherlands
Ingestion of lamp oil (intoxications)	Germany
Inherited hypocalemic salt-losing	Germany
Influenza infections(fatal/near fatal)	Spain

Intussuception	Switzerland
Invasive *Haemophilus influenzae* infection	Germany
Invasive fungal infections in VLBW infants	Britain
Invasive Group B streptococcal disease	Portugal
Juvenile Idiopathic Arthritis	Wales
Kawasaki Disease	Portugal
Kernicterus	Germany
Langerhans cell histocytosis	Britain
Lap-belt syndrome	Canada
Leukemia	Latvia
MCADD	Netherlands
Malaria	Netherlands
Measles(complications)	Germany
Medium-chain acyl-CoA dehydrogenase	Netherlands, Britain, Canada
Meningoencephalitis	Portugal
Munchausen by proxy syndrome	Australia
Necrotising enterocolitis	Papua New Guinea
Necrotising fascitis	Canada
Neonatal herpes simplex virus infection	Canada, Switzerland
Neonatal sinus venous thrombosis	Germany
Nephrology	Latvia
Neonatal liver failure	Canada
Nephrotic Syndrome (idiopathic)	New Zealand, Netherlands
Neural tube defects	Switzerland, Ireland
Opsoclonus myoclonus syndrome	Ireland
Osteogenesis imperfecta	Canada
Pneumococcal sepsis/meningitis	Germany
Prader-Willis Syndrome	Canada
Progressive intellectual and neurological	Canada
Prolonged Infantile Cholestasis	New Zealand
Rett syndrome	Australia
RSV virus	Switzerland
Septo-optic dysplasia	Wales
Severe combined immunodeficiency	Canada
Shaken Baby Syndrome	Switzerland, Netherlands, Wales
Thrombocytopenia	Ireland
Thrombosis(neonatal sinus venous)	Spain
Thyrotoxicosis	Britain
Tuberculosis	Britain

List of Clinicians with 100% Return Rate 2004 (& 2003)

Clinicians who had a 100% return rate in both 2003 and 2004 are underlined

Thank you to those clinicians who returned all of their cards in 2004!

Aftimos	Salim	Hassall	Ian	O'Donnell	Clare
Aho	George	Harris	Mark	Palmer	Penny
Aiken	Richard	Gunn	Alistair	Parsons	Alan
Asher	Innes	Hewson	Michael	Pattemore	Philip
Baker	Nicholas	Harding	Jane	Pinnock	Ralph
Barry	John	Hassall	Ian	Porteous	Louise
Bates	Giles	Hofman	Paul	Pringle	Kevin
Battin	Malcolm	Hoare	Simon	Robertson	Steven
Bhatia	Sat	Heron	Peter	Radcliffe	Marlon
Bourchier	David	Hornung	Tim	Ramadas	Ram
Bowkett	Brendon	Hunter	Warwick	Rowley	Simon
Bradley	Stephen	Jackson	Pam	Richardson	Vaughan
Broadbent	Roland	Jacquemard	Raimond	Richter	Stephanie
Broomfield	Frank	Jamison	David	Reith	David
Brown	Jeff	Jankowitz	Peter	Rudge	Susan
Buchanan	Leo	Kelly	Andrew	Salmon	Bernadette
Buckley	David	Kelly	Patrick	Selby	Robyn
Byrnes	Cass	Knight	David	Shaw	Ian
Calder	Louise	Kolbe	Anne	Shaw	Robyn
Campanella	Silvana	Kushel	Carl	Sinclair	Jan
Campbell-Stokes	Priscilla	Lees	Hugh	Sadlier	Lynette
Caseley	Terry	Lennon	Diana	Skeen	Jane
Clarkson	John	Leversha	Alison	Skinner	Jon
Corban	Jenny	Liang	Allen	Shillito	Paul
Corbett	Rob	Lourens	Ralph	St John	Martyn
Coulter	Belinda	McArthur	John	Stanley	Thorsten
Dalton	Marguerite	McFarlene	Scott	Stonehouse	Mary

Daniel	Alison	McIlroy	Peter	Stander	Heinrich
Darlow	Brian	MacKenzie	Neil	Taylor	Barry
De Sylva	Tony	Maikoo	Rajesh	Taylor	Paul
Denny	Simon	Marshall	Andrew	Teague	Lochie
Doran	John	Manikkam	Noel	Tomlinson	Paul
Drake	Ross	Maxwell	Fraser	Tuck	Roger
Edwards	Liz	Marks	Rosemary	Vogel	Alison
Elder	Dawn	Meyer	Michael	Walker	Wendy
Farrell	Alan	Mildenhall	Lindsay	Watson	Peter
Ferguson	Stuart	Mitic	Schumann	Webb	Alan
Ford	Rodney	Mitchell	Ed	Webster	Diane
Forster	Richard	Moyes	Chris	Wesley	Alison
Gavin	Raewyn	Morrison	Philip	Weston	Phillip
Gapes	Stephanie	Nagel	Fred	Wills	Russell
Gentles	Tom	Neutze	Jocelyn	Wilson	Callum
Gillies	John	Newman	David	Wilson	Nigel
Goldsmith	John	Nicholson	Ross	Wiltshire	Esko
Graham	David	Nicolls	Wayne	Wilson	Ross
Grant	Cameron	Nobbs	Peter	Wong	Maisie
Grimwood	Keith	Nutthall	Gabrielle	Wong	William
Hall	Kate	Moore	Philip		

Congratulations to Alan Farrell who was selected to win a $50 book token to be presented at the ASM of the Paediatric Society of New Zealand.

APPENDIX 1

COPY

The Royal Australasian
College *of* Physicians

25 September 2004

Associate Professor Elizabeth Elliott
Director Australian Paediatric Surveillance Unit
Department of Paediatrics & Child Health
The Children's Hospital at Westmead
Cnr Hawkesbury Rd & Hainsworth Street
WESTMEAD NSW 2145

Dear Professor Elliott

MOPS points for APSU activities

Thank you for your letter of 15 September, seeking clarification about MOPS points for activities completed for the APSU surveillance project.

Participating in the APSU/NZPSU activities will attract the following MOPS points:

- Half a point an hour (practice-related CME) for reading the protocol sheets on the conditions being studied and for submitting the monthly notification cards on occurrences of conditions being studied by the APSU/NZPSU
- Following notification of a case, half a point an hour (practice-related CME) for completing the follow up questionnaire on the condition, including time spent reviewing clinical notes and data collection. Eligibility for points is dependant on completing the follow-up questionnaire after notification of the case
- Quality assurance points may be claimed by the individual participant external to the ASPU surveillance activities if he/she documents how participation in the program has influenced his clinical practice.

With regards to developing multiple-choice questions for use by Fellows and Trainees, please contact Dr Raewyn Gavin, Chair of the PSAP Committee c/o the Paediatrics & Child Health Division at the College and Dr Andrew Kornborg, Chair of the Paediatrics Written Exam Committee at the College.

I hope this clarifies matters. Please contact me if you have any further questions.

Yours sincerely

Claire Wheeler
Senior Administrative Officer, Continuing Professional Development

cc. Dr Ralph Pinnock, NZPSU

APSU CME activities response
145 Macquarie Street, Sydney NSW 2000, Australia Tel: (61 2) 9256 5444 Fax: (61 2) 9252 3310 E-mail: racp@racp.edu.au Web: www.racp.edu.au
ACN 000 039 047 ABN 90 270 343 237

APPENDIX 2

PRELIMINARY RESULTS FROM THE EVALUATION QUESTIONNAIRE* FOR PARTICIPANTS OF NZPSU SCHEME

* BASED ON QUESTIONNAIRE DEVELOPED BY THE AUSTRALIAN PSU

Nature of Clinical Practice

	n	%
General	66	37.5
General & one or more subspecialty	41	23.3
Paediatric Subspecialist	57	32.4
Other Specialist	8	4.5
Community Child Practitioner	1	0.6
Other	2	1.1
Not in Practice	1	0.6
Total	176	100

Use, Value and Accessibility of Protocols, Case Definitions (including diagnostic criteria) and Questionnaires

Read the study protocols and questionnaires

	n	%
Always	46	26.1
Most of the time	70	39.8
Sometimes	51	29.0
Never	5	2.8
Not answered	4	2.3
Total	176	100

Educational usefulness of protocols

	n	%
Always	10	5.7
Sometimes	66	37.5
Never	8	4.5
Not answered	8	4.5
Total	176	100

Protocols kept in an accessible place

	n	%
Always	60	34.1
Most of the time	45	25.6
Sometimes	25	14.2
Never	40	22.7
Not answered	6	3.4
Total	176	100

Annual Report

Received previous year's (2002) NZPSU Annual Report

	n	%
Yes	112	63.6
No	12	6.8
Don't know/Can't remember	49	27.8
Not answered	3	1.7
Total	176	100

Read previous year's NZPSU Annual Report

	n	%
Yes all	10	5.7
Yes - some	98	55.7
Don't know/Can't remember	48	27.3
No	17	9.7
Not answered	3	1.7
Total	176	100

How informative was previous year's NZPSU Annual Report (limited to those who had read "all" or "some" of the previous year's report)

	n	%
Very	45	41.7
Somewhat	55	50.9
Don't know/Can't remember	7	6.5
Not at all	1	0.9
Total	108	100

Results of Studies

Where results were seen

	n	%
The medical literature	24	13.6
Presentations/posters at Paediatric Society Meetings	80	45.5
NZPSU Annual Reports	104	59.1
Other Scientific Meetings	6	3.4
Other	6	3.4

Total of percentages >100% as people could indicted more than one

Protocols or the findings of any NZPSU study informed or changed clinical practice.

	n	%
Yes	21	11.9
Don't know/Can't remember	37	21.0
No	111	63.1
Not answered	7	4.0
Total	176	100

Participants felt adequately acknowledged in presentations/publications/NZPSU Annual Report)

	n	%
Yes	105	59.7
No	5	2.8
Don't Know	52	29.5
Not answered	14	8.0
Total	176	100

Monthly reporting

How monthly report card received

	n	%
Post	49	27.8
Email	122	69.3
Not answered	5	2.8
Total	176	100

Preference for email (Limited to those who received card by post)

	n	%
Yes would prefer email	38	77.5
No	10	20.4
Not answered	1	2.0
Total	49	100

Could the current format of emailed card be improved?

(Limited to those who received card by email)

	n	%
Yes	4	3.3
No	101	82.8
Not answered	17	13.9
Total	122	100

Completing and returning the NZPSU report cards a burden

	n	%
No	154	87.5
Sometimes	10	5.7
Yes	2	1.1
Not answered	10	5.7
Total	176	100

Willing to report more cases by fax/phone (as currently for AFP) if an important reason is provided?

	n	%
Yes	118	67.0
No	23	13.1
Don't Know	24	13.6
Not answered	11	6.3
Total	176	100

Would object to collection samples (including blood) for other conditions? (Acute Flaccid Paralysis (AFP) surveillance requires a stool, specimen be sent to ESR)

	n	%
No	122	69.3
Yes	17	9.7
Don't Know	25	14.2
Not answered	12	6.8
Total	176	100

Concern about providing de-identified clinical information

	n	%
No	146	83.0
Yes	6	3.4
Unsure	18	10.2
Not answered	6	3.4
Total	176	100

Ever known of a case but chosen not to return the card or make a report

	n	%
No	163	92.6
Yes	6	3.4
Not answered	7	4.0
Total	176	100

Regarding the number of conditions on the card

	n	%
More would be fine	71	40.3
The current number	83	47.2
There should be fewer	14	8.0
Not answered	8	4.6
Total	176	100

Ever considered conducting a study through the NZPSU, but did not

	n	%
No	140	79.5
Yes	26	14.8
Not answered	10	5.7
Total	176	100

Responses of those who had ever reported a case

Ever too long a delay between reporting a case and receiving a questionnaire

	n	%
No	67	69.0
Yes	18	18.5
Don't Know	12	12.3
Total	97	100

Questionnaire(s) easy to complete

	n	%
Yes	57	58.7
No	28	28.8
Don't Know	12	12.3
Total	97	100

Case specific data always readily available

	n	%
Yes	48	49.4
No	25	25.7
Don't Know	24	24.7
Total	97	100